AD_____

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TITLE: Enhancing Involvement in Treatment Decision Making by Women with Breast Cancer

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13. SUPPLEMENTARY NOTES

14. ABSTRACT Purpose: Women with breast cancer desire more information about their disease, in part, to be involved in making treatment decisions (TDs). Patient involvement responds to patients' desires for autonomy and addresses ethical concerns about rights to make TDs. However, several researchers have reported that patients' actual experiences in TDM did not match their preferences. The study objectives are to 1) understand the meaning of involvement in TDM from the perspectives of women with early stage breast cancer (ESBC); 2) identify stages/ steps of TDM used by women and their physicians during the treatment consultation(s); and 3) identify the behaviors of women and physicians that facilitate or impede women's involvement in TDM. Methods: A qualitative approach with interviews and video-stimulated recall is being used. In Phase 1, interviews with 19 women with ESBC were held to understand the concept of involvement in TDM. In Phase 2, surgical (n=6) or medical oncology (MO) consultations (n=15) with new ESBC patients were videotaped. Subsequently, women and medical oncologists or surgeons separately viewed their consultation. Interviews were taped, transcribed, and analyzed. Findings: Phase 1: Most women wanted high quality information soon after diagnosis but many felt isolated and uninformed until the surgical or the medical oncology visit. In Phase2, most women described an iterative TDM process where they made a preliminary treatment decision prior to the consultation, often based upon experiences of family or friends. Clinicians described many behaviours used to facilitate the patient's involvement in TDM. While women reported some of these behaviours, they also reported fewer or different behaviours than clinicians. Significance: The information from this study will be useful to patients and physicians for promoting patient involvement. It can be used to develop and evaluate training programs for both physicians and patients to involve patients with cancer in decisions about their care.

15. SUBJECT TERMS
Treatment Decision Making, Video-Stimulated Recall Interviews, Patient Participation, Behavior Identification

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Table of Contents

Introduction

This report summarizes the research accomplishments of the second year of the Predoctoral Traineeship Award, from July 1 2006 to June 30 2007. The training studentship is a doctoral degree in Health Research Methodology at McMaster University in Hamilton, Canada.

The overall goal of the thesis proposal is to improve the opportunity for patient involvement in treatment decision making (TDM) for women with early stage breast cancer (ESBC). The specific objectives are 1) to describe the meaning of involvement in TDM from the perspectives of women with ESBC, 2) to identify the processes or stages of TDM used by women and their physicians and 3) to identify the behaviors of women and their physicians that facilitate or impede women's involvement in TDM. In this report, the results of Task 2 (Objective 2) from the Statement of Work will be summarized. The second task was to complete patient recruitment, data collection and analysis for the Phase 2 patient and clinician interviews.

Statement of Work Task 2, Phase 2 (Video-Stimulated Recall Interviews with Patients and Physicians: Patient Recruitment, Data Collection, and Analysis (Months 10-24)

Patient Recruitment: A process for patient recruitment was developed in Phase 1. A similar process was used in Phase 2. Briefly, the PI met with medical oncologists as well as surgeons to explain the purpose of Phase 2 of the study. The PI also presented the study to the primary nurses who were part of the clinical team to gain their support for the study and to enlist their help with the process to be used to identify eligible patients. The clinical features of all new patients were reviewed and those who appeared to meet the inclusion criteria (refer to the Phase 2 Eligibility Form in the Appendices) were identified by a research assistant. Prior to each eligible patient's scheduled visit, the oncologist or surgeon was asked for his or her permission to approach the patient about the study and for his/her consent to participate in the study. If the clinician agreed, then the patient was approached by the oncologist, surgeon or the primary nurse. If the patient expressed interest in the study, then a research assistant explained the purpose of the study and obtained consent. For consenting patients and clinicians, the consultation was videotaped. Subsequently, women and surgeons or medical oncologists separately viewed their videotaped consultation with the researcher. While watching their video, each woman and clinician was interviewed by the researcher about the consultation process. The video was paused at various pre-selected stopping points to facilitate discussion of TDM and key clinician facilitators and barriers. The setting for the study was a regional cancer centre

(Juravinski Cancer Centre (JCC)) and a teaching hospital (St. Joseph's Hospital) in Hamilton, Ontario.

Data Collection

Pilot –Testing: The interview guide was pilot-tested with five patients who were completing chemotherapy treatment. Subsequently, the guide was revised (refer to the Phase 2 Interview Guide in the Appendices). Data collection for the study began shortly thereafter.

All patients who signed a consent form were interviewed by the PI using the revised interview guide. Interviews were held either at the JCC, McMaster University or in the patient's home according to the patient's preference. Each interview was audiotaped and transcribed verbatim. In addition, demographic and clinical data were collected. After each interview, notes were handwritten then transcribed.

In general, patients were selected to be approached for the study if they met the inclusion criteria and the clinician agreed to approach the patient. As well, patients were selected in a purposeful manner so that both node-negative and node-positive patients in different age groups were included among women making an adjuvant therapy decision.

Analysis

The analysis was conducted using a grounded theory approach (Charmaz 2006; Glaser and Strauss 1967). A brief coding guide developed for Phase 1 was adapted for Phase 2. Two analysts independently coded two entire transcripts. The codes were compared and agreement was reached. In a similar manner, categories were generated from the codes, the results were compared, and agreement was reached. To check the stability of the process, a section from a third transcript was coded independently by the same two analysts and the results were compared. One analyst coded the remaining transcripts. Substantive coding was used to identify themes and sub-themes from the data. Selective coding was used to identify a central theme and causal conditions that influenced the central theme and resulting actions.

Results

Twenty-two women with ESBC were enrolled in this phase and 21 completed the study. Fifteen women made a decision about adjuvant therapy and six made a decision about surgery. One patient was excluded after videotaping because of a tape failure. Of the women who made

an adjuvant therapy decision, six had node negative disease and nine had node positive disease.

The following section highlights several examples of themes in the categories of stages/steps of TDM and clinician facilitators and barriers to women's involvement in TDM.

A. Stages/Steps of Treatment Decision Making

Most women described an iterative TDM process in which information was gathered from informal networks and preferred and non-preferred treatment options were identified prior to formal consultations. Preferred treatment options were confirmed or reassessed at the surgical and MO consultations after receiving information from the specialist. Surgical decisions were confirmed in the surgeon's office on the same day. In contrast, most women described deliberation process about adjuvant treatment both during the MO consult and at home with a treatment decision reached at home several days after the MO consult. Most women continued to revisit their treatment decision after the formal surgical or MO consultation.

Prior to the surgical and MO consultations, women sought information about treatment options from informal networks of family or friends.

Prior to the surgical consult, there was no systematic process whereby women accessed high quality information about treatment options. Women obtained information about surgical options from their informal network. Before the MO consult, most women described fears about chemotherapy based on others' negative experiences. Many women thought chemotherapy was only offered in serious cases and others thought that it might shorten their life.

Most women identified preferred and non-preferred treatment options prior to formal consultations.

Women wanted treatment that would give them the best chance of eliminating cancer. They considered their family doctors' preferences for treatment and opinions about treatment effectiveness from family and friends. Regarding surgery, women identified a preferred type of surgery before the consultation which was later confirmed with the surgeon. In contrast, most women had a preference for or against chemotherapy in general but not the type of chemotherapy. In both surgical and MO settings, women did not change their preferred option after the formal consultation unless new or conflicting information was received.

Discussions with the surgeon were important to subsequent TDM.

During the surgical follow-up visit, women formed an opinion about the 'aggressiveness' of the cancer and the need for further treatment. If women heard the surgeon mention that chemotherapy might be offered by the medical oncologist, they were prepared for any subsequent discussion. If treatment options or tumor-related information given by the medical oncologist were different from those expected, it was confusing for women.

Chemotherapy consultations were important to TDM but were also overwhelming and complex.

Despite efforts by medical oncologists to transmit information clearly, both women and oncologists believed that the consultations were information-dense. Women were overwhelmed by the amount of information and found it difficult to think about treatment options during the consultation. Women frequently misinterpreted or forgot information given.

B. Clinician Facilitators and Barriers to Women's Involvement in TDM

Women's Views: Facilitators

The most common facilitators were:

- Prepared her for chemotherapy discussion (family doctor and surgeon)
- Made her feel comfortable e.g. making eye contact, friendly and relaxed manner
- Gave clear explanations about the disease, risk of recurrence (MO), and treatment options
- Encouraged her to process information about options e.g. explaining the DM context, using visual aids, and encouraging her to take enough time
- Gave her a clear treatment recommendation which helped her focus on options that were most suited to her preferences
- Provided reassurance by stating that he/she agreed with her decision

Women's Views: Barriers

Generally few clinician barriers were mentioned. The most commonly noted barriers were insufficient use of visual aids by clinicians, mismatch of information in discussion and take home material, and not acknowledging women's expectations. Women also mentioned system barriers including lack of access to information prior to surgical and MO consults.

Clinicians' Views

Clinicians described similar categories but more facilitating behaviours related to information-giving and processing than women. Clinicians relied on verbal explanations rather than visual aids. They described fewer interpersonal behaviors such as making women feel comfortable and providing reassurance.

Key Research and Training Accomplishments

1. Successfully competed all PhD course requirements with an 'A' standing or higher (previous report).
2. Successfully completed the PhD comprehensive examination (previous report).
3. Thesis related tasks:
    a. Completed Phase 1 data collection (previous report).
    b. Developed a process to videotape consultations of women with ESBC.
    c. Completed pilot testing for Phase 2.
    d. Completed Phase 2 interviews of 21 women with ESBC and their oncologist or surgeon. These interviews identified stages/steps in TDM used by these women as clinician facilitators and barriers to their involvement in TDM.
4. As part of my training program, I participated in other research projects that resulted in podium or poster presentations at conferences.
5. Also as part of my training program, I reviewed several manuscripts and a national grant application in conjunction with my supervisor.

Reportable Outcomes

Conference Presentation Abstracts

2007 O'Brien MA, Whelan TJ, Charles C, Ellis P, Gafni A, Lovrics P, Hasler A, Dimitry S. Through the looking glass : using video-stimulated recall to explore women's decision making about breast cancer treatment about breast cancer treatment. Proceedings of the 4th International Shared Decision Making Conference, Freiburg, Germany.

2007 Ellis P, Dimitry S, Charles C, O'Brien MA, Whelan T. What can physicians do to facilitate patient involvement in treatment decision making in the oncology consultation? Proceedings of the 4th International Shared Decision Making Conference, Freiburg, Germany.

2006 O'Brien MA, Whelan TJ, Charles C, Ellis P, Gafni A, Lovrics P, Dimitry S, Hasler, A. Enhancing involvement in treatment decision making by women with breast cancer. Proceedings of the Society for Medical Decision Making annual conference. Cambridge, MA.

Awards

2007 Juravinski Cancer Centre. Student Research Day. One of four best research presentations.

Conclusions

In summary, considerable progress has been made during the second year of the Predoctoral Traineeship Award as noted in the section on Key Research and Training Accomplishments. We were able to successfully recruit patients and clinicians from the JCC and St. Joseph's Hospital. Data collection is complete for Phase 2 and an analysis has been conducted. As contained in the previous report, all PhD course requirements have been successfully completed as has the comprehensive examination. The study has received the support from the oncologists and nurses at the JCC as well as surgeons at HHS and St. Joseph's Hospital. This support was crucial to the successful completion of the video-stimulated recall interviews.

References

Charmaz K. Constructing grounded theory. Sage Publications, Thousand Oaks, CA., 2006.
Glaser B and Strauss A. Discovery of grounded theory: strategies for qualitative research. Aldine Publishing Company, Chicago, IL., 1967.

Appendices

1. Phase 2 Eligibility Form
2. Phase 2 Interview Guide
3. CV
4. Abstracts

Appendices

Enhancing Involvement in Treatment Decision Making by Women with Breast Cancer

Patient Initials: __ __ __ **Phase 2** **Study ID Number: __ __ __ __**

ELIGIBILITY ASSESSMENT

To be completed for all patients who meet the Inclusion Criteria

SECTION 1: INCLUSION CRITERIA

Answer EACH criterion listed below:

The patient:	YES	NO
1a) Is female.	❑ 1	❑ 2
1b) Has histologically documented invasive carcinoma of the breast.	❑ 1	❑ 2
1c) Is Stage I, Stage II, or Stage III a and eligible for surgery, chemotherapy or radiation therapy.	❑ 1	❑ 2

If all answers are "Yes" continue to SECTION 2. If at least one "No" answer, patient is not eligible, do not continue.

SECTION 2: EXCLUSION CRITERIA

Answer EACH criterion listed below:

The patient:	YES	NO
2a) Is Stage III b, c or Stage IV	❑ 1	❑ 2
2b) Is unable to speak or understand English fluently (including visual impairment).	❑ 1	❑ 2
2c) Is mentally incompetent including any psychiatric or addictive disorders that would preclude taking part in an interview.	❑ 1	❑ 2

Continue to SECTION 3

SECTION 3: ELIGIBILITY STATUS

3a) Is the patient eligible to participate in the study?
(i.e., all Inclusion Criteria are answered "Yes" and all Exclusion Criteria answered "No")

❑ 1 Yes → *Continue to SECTION 4 PATIENT CONSENT*

❑ 2 No → *Sign and date form*

SECTION 4: PATIENT CONSENT

4a) Has the patient provided written informed consent?

- ❑ 1 Yes → **Include**
- ❑ 2 No → *Please provide reason:*
  - o 1 Physician did not want the patient to be approached
  - o 2 Patient did not want to consent
  - o 3 Other: _____

SECTION 5: Identification

Study ID Number: __ __ __ __

Cancer Centre Chart Number: __ __ · __ __ __ __ __ __

Date of Eligibility Assessment __ __ / __ __ __ / __ __ __ __
day *month* *year*

Signature of person completing form: _____

Date form completed: __ __ / __ __ __ / __ __ __ __
day *month* *year*

Study Title: Enhancing Involvement in Treatment Decision Making by Women with Breast Cancer

Phase 2: Patient Interview Guide and Video- Stimulated Recall

Greetings

Introduction

As you know, this is a study about how women make decisions about breast cancer treatment and how they want to be involved in that process. In this interview, you and I will have a short discussion about your decision making process, then we will watch a DVD of your consultation with Dr ____. If there are any questions that you do not want to answer, we will just skip to the next question. If you would like to have a rest at any time, just let me know. After we watch the DVD, there are other questions that I will ask you about the decision making process.

Opening Question

1. From your perspective, did you have any goals for the consultation with Dr. _____? If yes, what were they? If no, what did you think would happen at the consultation? (this question was not used in Pilot but suggested by D. Feldman-Stewart Feb 2006 to provide context)

Decision making process related to cancer treatment

1. With respect to your consultation with Dr. ____do you feel that there were decisions that were made about your treatment?
   Prompts: If yes, can you tell me about the decision that was made?
   If no, can you tell me why you felt there was no decision to be made?

Now, we will watch the DVD of your consultation with Dr. ____. I want you to stop the DVD any time that you feel that you or the doctor was taking part in the process of making a decision about treatment. I also want you to stop the DVD if the doctor was doing anything or saying anything that either helped you to take part or made it harder for you to take part in the process of decision making. [Give instructions to the patient]

[Watch DVD]

[After the DVD, the following questions will be asked if they were not addressed while watching the DVD]

If there was a decision about treatment

2. In your situation, can you describe the process of making the decision about treatment?
   Prompts: Possibilities: asking for and receiving information about treatment options, deliberating over the options, making the decision.
   Alternative questions: How was a decision about treatment made? How did you decide what to do?

3. Were there clear steps that you went through in order to make this decision?
   a. Prompts: If Yes what were the steps?
   b. If yes, how do these steps relate to each other (a sequence, steps happening simultaneously?)
   c. Was one step more important than another?
   d. If No, how did you arrive at a treatment decision?

4. The doctor gave you some information about the chance of the cancer returning. Did you use this information in your decision making process?
   a. *Prompts*: If yes, how did your use this information?
   b. *Prompts*: If no, why was that?

5. The doctor gave you some information about side effects of treatment. Did you use this information in your decision making process?
   a. *Prompts*: If yes, how did your use this information?
   b. *Prompts*: If no, why was that?

6. Who was involved in the process of making the decision?
   Prompts: Patient, doctor, primary care nurse, family, others?

7. Where did the process of decision making take place?
   Prompts: At home, at the cancer centre, both places?

8. When did the process of decision making first start?
   Prompts: When patient had symptoms, at the oncologist's office

9. When did the process of decision making end?

10. In summary, did you feel that you took part in the process of making a treatment decision?
    Prompts: If yes, can you tell me all the ways that you took part? Was it how you wanted to take part?
    Prompts: If no, why was that? Did you take part more than you wanted or less than you wanted? If more than you wanted, how did that happen? How did you feel about taking part more than you wanted? If less than you wanted, how did that happen? What sort of things prevented you from taking part?

11. If you took part in the process of making a decision as much as you wanted, did the doctor say or do anything to help you to take part in the process of making a decision about treatment?

12. Did the doctor say or do anything to discourage you from taking part in the process of making the decision about treatment?

13. Is there any feature about you as a person that helped you to take part in the process of making the decision about treatment?
    Prompts: For example, a patient who wants to know all treatment details or does not want to know; The patient's previous personal or family member's experience.

14. Is there any feature about you as a person that acted as a barrier to you taking part in making a decision about treatment?

15. Did your involvement in the process of making a decision about treatment change since you first learned you had breast cancer?
    Prompts: When you saw the surgeon, when you saw the oncologist

16. Did you have enough time to take part in the process of making a decision about treatment?

17. Overall, now thinking about the decision making process, what is needed for a process that is high in quality?
    Prompt: what did you find helpful in the decision making process?

18. How would you describe the quality of the decision making process that you used?
    Prompt: Why do you feel this way?

Closing

19. Is there anything else you would like to tell me about your situation of making a treatment decision?

Thank you once again for participating in my study.

Instructions:

Now, we will watch the DVD of your consultation with Dr. ____.

I want you to stop the DVD any time if

1. **You feel that you were taking part in the process of treatment decision making.**

2. **You feel that the doctor was taking part in the process of treatment decision making.**

3. **The doctor did or said anything that helped you to take part in the process of treatment decision making.**

4. **The doctor did anything or said anything that made it harder for you to take part in the process of treatment decision making.**

CURRICULUM VITAE

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EDUCATIONAL BACKGROUND

2003 PhD in progress (commenced September 2003)

1995 MSc (Design, Measurement and Evaluation), McMaster University, Hamilton, Canada

1984 BHSc (Physiotherapy) McMaster University, Hamilton, Canada

1978 Diploma in Physiotherapy, Mohawk College, Hamilton, Canada

Certificate in Physiotherapy, McMaster University, Hamilton, Canada

CURRENT STATUS AT MCMASTER UNIVERSITY

2001-2006 Associate Clinical Professor, School of Rehabilitation Science

1998-2001 Assistant Clinical Professor, School of Rehabilitation Science

1992-1997 Clinical Lecturer, School of Rehabilitation Science

EMPLOYMENT HISTORY

ACADEMIC

2000- 2003 Senior Research Manager, Supportive Cancer Care Research Unit, McMaster University

1999- 2000 Research Co-ordinator, Evidence-based Practice Centre, McMaster University

1998-1999 Research Co-ordinator, McMaster University and Social and Public Health Services Division, Region of Hamilton-Wentworth

1997-1998 Senior Research Fellow, Department of Public Health, University of Aberdeen, United Kingdom

1996-1997 Research Fellow, Department of Health Sciences and Clinical Evaluation, University of York, United Kingdom

1985-1991 Clinical Education Co-ordinator, Mohawk-McMaster Physiotherapy Program, Mohawk College of Applied Arts and Technology, Hamilton, Ontario

CLINICAL

1999- Physiotherapist, Hamilton Health Sciences

1996-1997 Evaluation Specialist, Re-engineering Department, Chedoke-McMaster Hospitals

1991-1996 Education Manager, Physiotherapy Services, Chedoke-McMaster Hospitals

1985-1991 Clinical Education Co-ordinator, Chedoke-McMaster Hospitals, McMaster University Medical Centre Division

1983-1985 Senior Physiotherapist, Chedoke-McMaster Hospitals, McMaster University Medical Centre Division

1978-1983 Staff Physiotherapist, Chedoke-McMaster Hospitals, McMaster University Medical Centre Division

AWARDS AND FELLOWSHIPS

2005 – 2008 Predoctoral Traineeship Award, US Department of Defense, Breast Cancer Research Program

2004 – 2006 Doctoral Fellowship, Canadian Breast Cancer Foundation – Ontario Chapter (declined Year 2)

2004 – 2007 Doctoral Studentship, National Cancer Institute of Canada (declined)

2004 – 2005 Ontario Graduate Student Award, (declined)

SCHOLARLY AND PROFESSIONAL ACTIVITIES

1997- Peer Reviewer
Grants: National Health Service Research & Development Programme, National Health Service Health Technology Assessment Programme, United Kingdom
Manuscripts: American Journal of Public Health, Health and Social Care in the Community, Journal of Epidemiology and Community Health, Medical Care, Quality in Health Care

1995-2002 Member, Board of Examiners, Physiotherapy National Exam.

1995-1997 Chief Examiner, Clinical Component, Physiotherapy National Exam, Toronto Site.

1991-1995 Member, Clinical Education Group, Physiotherapy Programme, School of Occupational Therapy and Physiotherapy, McMaster University, Hamilton, Ontario.

1990-1995 Chair, Station Development Sub-Committee, OSCE Test Construction and Implementation, Canadian Alliance of Physiotherapy Regulatory Boards.

AREAS OF INTEREST

RESEARCH

Attributes of the clinical encounter that facilitate treatment decision-making
Effectiveness of interventions to improve health professional practice
Factors influencing the adoption of research evidence into health professional practice

TEACHING

Finding the best available evidence and incorporating it in clinical practice

COURSES TAUGHT

McMaster University (Graduate)

2004-	Lecturer, Inquiry Seminar, MSc. PT Programme
2003- 2003	Tutor, Unit Three, Introduction to Cardio-pulmonary and Neurology, MClSc PT Programme
2000	Co-Advisor with A Jadad, Research Internship, Health Research Methods Programme

University of Aberdeen (Graduate)

1997	Lecturer, Health Services Research

McMaster University (Undergraduate)

2001	Tutor, Unit Four, Cardio-pulmonary, BHSc. PT Programme
2000- 2003	Inquiry Seminar, BHSc. PT Programme
2000	Advisor, Unit Six Research Internship
1998-1999	Tutor, Unit Four, Cardio-pulmonary, BHSc. PT Programme
1996	Advisor, Unit Six, Independent Study, BHSc. PT Programme
1993-1995	Tutor, Unit Four, Cardio-pulmonary, BHSc. PT Programme
1992	Advisor, Block Six, Independent Study, BHSc. PT Programme
1990-1992	Tutor, Block One, Introduction to Musculo-Skeletal Problems, BHSc. PT Programme
1988	Tutor, H.S. 4B4/3B4, Health, Science and Society, BHSc Programme

Other

1988-1995	Tutor, Clinical Teaching Workshop, Program for Faculty Development, McMaster University, Hamilton, Ontario

Thesis Committee

2000	Jodi Herold. The effect of using an alternative method to calculate station cut scores in an objective structured clinical examination (OSCE). (Masters) University of Toronto.

LIFETIME RESEARCH FUNDING

GRANTS

Funded

Funding Agency: Canadian Health Services Research Foundation
Funding Period: November 1 2004 to October 31 2006
Project Title: A Study of the Effectiveness of Specialist Oncology Nursing Case Management in Improving Continuity of Supportive Cancer Care in the Community

Investigators: Sussman J, Howell D, Brazil K, Whelan T, Green E, MacKenzie L, O'Brien MA, Wiernikowski J, Fitch M.

Funding Agency: Ontario Ministry of Health and Long-Term Care
Funding Period: January 2004 – June 2004
Project Title: e-Health and mental Health Services: A synthesis of literature to identify best practices.
Investigators: Raina P, Eysenbach G, Suggs LS, McIntyre C, MacMillan H, McKibbon KA, O'Brien MA, Santaguida L.

Funding Agency: Ministry of Health and Long Term Care
Funding Period: April 1 2003-March 31 2004
Funds Held in Department of Clinical Epidemiology and Biostatistics
Project Title: An Evaluation of the Effectiveness of a Specialized Nursing Case Management Program in Coordinating Supportive Cancer Care in the Community.
Investigators: Sussman J, O'Brien MA, Howell, D, Whelan T.

Funding Agency: Hamilton Regional Cancer Centre Foundation
Funding Period: April 1 2003- March 31 2004
Funds Held at the Hamilton Regional Cancer Centre
Project Title: Can Physicians Accurately Record Breast Cancer Outcomes? A Quality Improvement Pilot Study.
Investigators: O'Brien MA, Whelan T, Strang B, Wiernikowski J, Banayan D, Eisen A, Sussman J, Ellis P, Dubois S.

Funding Agency: Ministry of Health and Long Term Care
Funding Period: April 1 2001-March 31 2003
Funds Held in Department of Clinical Epidemiology and Biostatistics
Project Title: Identifying the best model to provide (coordinate) supportive cancer care in the community
Investigators: Brazil K, Whelan T, O'Brien MA, Sussman J, Pyette N.

Funding Agency: Agency for Healthcare Research and Quality
Funding Period: April 1 2001-March 31 2002
Funds Held in Department of Clinical Epidemiology and Biostatistics
Project Title: Diffusion and Dissemination of Evidence-based Cancer Control Interventions
Investigators: Ellis P, Raina P, Haynes RB, Brouwers M, O'Brien MA, Ciliska D, Browman G, Whelan TJ, Snider A, Rand C.

Funding Agency: Agency for Healthcare Research and Quality
Funding Period: April 1 2000-March 31 2001
Funds Held in Department of Clinical Epidemiology and Biostatistics
Project Title: Impact of Cancer-related Decision Aids
Investigators: Whelan TJ, Gafni A, Charles C, Jadad A, O'Brien MA

Funding Agency: Agency for Healthcare Research and Quality
Funding Period: September 30 1999-September 29 2000
Funds Held in Department of Clinical Epidemiology and Biostatistics
Project Title: Management of Chronic Central Neuropathic Pain Following Spinal Cord Injury
Investigators: Jadad A, O'Brien MA. Snider A, Gauld M

Funding Agency: Canadian Health Services Research Foundation
Funding Period: November 1999-November 2000

Project Title: Improving Communication Among Public Health Researchers and Decision and Policy Makers.
Investigators: Thomas BJ, O'Brien MA, Edwards N., Ciliska D., Dobbins M., Beyers J.

Funding Agency: CMH Physiotherapy Grant Fund
Funding Period: July 1996-July 1997
Funds Held in CMH Physiotherapy Department
Project Title: Diagnostic Validity of Clinical Tests in Temporomandibular Disorder: meta-analyses
Investigators: Gross A, Haines T, Goldsmith C, McIntosh J, Thomson MA.

Funding Agency: Heart and Stroke Foundation of Ontario
Funding Period: July 1996-July 1998
Project Title: Stroke Strengthening Study
Investigators: Moreland J, Cook DJ, Goldsmith C, Thomson MA, Huijbregts M, Anderson R, Prentice D.

Funding Agency: National Health Service, Research and Development, United Kingdom
Funding Period: January 1996 - January 1997
Funds held at University of York, United Kingdom
Project Title: The Effectiveness of Continuing Education Conferences in Improving Health Professional Performance and Health Care Outcomes
Investigators: Thomson MA, Freemantle N, Oxman AD, Davis DA.

Funding Agency: Canadian Orthopaedic Foundation, Hip, Hip Hooray Grants Program
Funding Period: July 1995-July 1996
Funds Held in CMH Physiotherapy Department
Project Title: Diagnostic Validity of Clinical Tests in Temporomandibular Disorder: meta-analyses (1995 update)
Investigators: Gross A, Haines T, Goldsmith C, McIntosh J, Thomson MA.

Funding Agency: Canadian Orthopaedic Foundation, Hip, Hip Hooray Grants Program
Funding Period: July 1993 - June 1994
Funds held in Physiotherapy Department, Chedoke-McMaster Hospitals
Project Title: Lower Extremity Function Study
Investigators: Thomson MA, Moreland J, Balsor B, Kay, T.

Funding Agency: Edith Herman Research Fund, McMaster University, Hamilton, Ontario
Funding Period: December 1993 - December 1994
Funds held in Faculty of Health Sciences, School of Occupational and Physiotherapy
Project title: Diagnostic Validity of Clinical Tests in Temporomandibular Disorders: Meta-analyses
Investigators: Gross A, Haines T, Goldsmith C, McIntosh J, Thomson MA.

Funding Agency: Hamilton District Research Fund, Ontario Physiotherapy Association, Hamilton, Ontario
Funding Period: June 1992 to June 1993

Funds held by Hamilton District Treasurer
Project title: Diagnostic Validity of Clinical Tests in Temporomandibular Disorders: Meta analyses
Investigators: Gross A, Haines T, Goldsmith C, McIntosh J, Thomson MA.

Funding Agency: Hamilton District, Ontario Physiotherapy Association
Funding Period: January 1992 - December 1992
Funds held in Physiotherapy Department, Chedoke-McMaster Hospitals
Project Title: The Efficiency of EMG Biofeedback for Upper Extremity Function Following Stroke: A meta-analysis.
Investigators: Moreland J, Thomson MA.

Submitted

Funding Agency: CIHR

Funding Period: October 1 2006 – September 30, 2011
Funds held in Department of Surgery, McMaster University
Project Title: Tailored Knowledge Exchange in Rectal Cancer (TKRC) Trial
Investigators: Simunovic M, O'Brien MA, Eva K, Whelan T, Koru-Sengal T, Goldsmith C, Thebane L, Lavis J, DeNardi F, Stern H, Smith AJ, Baxter N, Levine MN.

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Title: The efficiency of EMG biofeedback for lower extremity function following stroke: a meta-analysis. Investigators: Moreland J, Thomson MA, Fuoco A. Location: Chedoke-McMaster Hospitals

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Through the looking glass: using video-stimulated recall to examine women's decision making experiences about breast cancer treatment

O'Brien MA[1], Whelan T[1], Charles C[2], Ellis P[1], Gafni A[2], Lovrics, P[3],Hasler A[1], Dimitry S[1].
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Background: Women with breast cancer (BC) desire information, in part, to be involved in treatment decision making (TDM). However, several researchers have reported that patients' actual experiences in TDM did not match their preferences. This study's objectives were to identify stages/steps of TDM used by women with BC and to identify physicians' behaviours that facilitated or impeded women's involvement in TDM. **Methods**: A qualitative approach with video-stimulated recall interviews was used. Surgical (n=6) or medical oncology (MO) consultations (n=15) with new BC patients were videotaped. Subsequently, women and physicians separately viewed their consultation. Interviews were taped, transcribed, and analyzed. **Results**: Most women described an iterative TDM process where they made a preliminary treatment decision prior to the consultation, often based upon experiences of family or friends. Women wanted high quality information soon after diagnosis to assist with TDM but many felt uninformed prior to the consultation. Clinicians described many behaviours used to facilitate the patient's involvement in TDM. While women reported some of these behaviours, they also reported fewer or different behaviours than clinicians. Some women perceived that family physicians and surgeons helped their involvement in TDM in subsequent MO consultations. **Conclusion**: Many women perceived that they did not receive information relevant for TDM when it was most useful. Clinicians and women have different views of how clinicians facilitated women's involvement in TDM. Family physicians and surgeons are important in the TDM process by ensuring that women have early access to high quality information about different aspects of treatment.

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What can physicians do to promote patient involvement in decision making (DM) in the oncology consultation

Ellis PM, Dimitry S, Charles C, O'Brien MA, Whelan TJ.

Background
Promoting patient involvement in DM is a desirable attribute of the oncology consultation. Greater involvement in DM may lead to improved patient satisfaction and reduced psychological morbidity. However, there is little empiric evidence on physician behaviors to promote patient involvement in treatment DM. This study used qualitative methods to identify physician characteristics important for patient involvement in DM.

Methods
We undertook semi-structured interviews with 11 medical and 10 radiation oncologists, plus 19 patients with breast, lung, GI, or GU cancers to determine physician attributes that promote patient involvement in DM. Interviews were audiotaped and transcribed verbatim, then analyzed independently by two researchers using predetermined coding rules. Individual attributes describing physician behaviors were identified and coded into common themes. These data were reviewed by an additional 37 patients participating in one of six focus groups.

Results
A total of 231 individual physician attributes were identified by physicians (179) and patients (52) that might facilitate patient involvement in DM. Common themes about physicians' behavior identified from the interviews include: assess patient's understanding and preferences, provide information, explain DM process, provide information on treatment options, allow time to consider treatment options, physicians' communication skills and personality, check patient understanding of options, seek patient input into decision, be empathic.

Conclusions
Physicians and patients identify a large number of physician attributes to promote patient involvement in DM. These include both skills that are important in general physician-patient communication, as well as skills that are specifically related to the decision making process. Further research is needed to determine the relative importance of these factors.

Enhancing Involvement in Treatment Decision Making by Women with Breast Cancer

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Women with breast cancer have indicated a desire for more information about their disease, in part, to be involved in making treatment decisions. Importantly, patients who are involved in treatment decision making (TDM) are more likely to have their preferences incorporated in the treatment decision. Despite patients' desires to be involved in TDM and the ethical and medical importance of this involvement, researchers have reported that patients' actual experiences in making decisions did not match their preferences. The study objectives are to 1) understand the concept of involvement in TDM from the perspectives of women with early stage breast cancer (ESBC); 2) identify any stages or steps of DM used by women and their physicians during the treatment consultation(s); and 3) identify the behaviours of women and physicians that facilitate or impede women's involvement in TDM. A qualitative approach with interviews and video-stimulated recall was used. In Part 1, interviews with 19 women with ESBC were held to develop the concept of involvement in TDM and the decision making process used by these women. In Part 2, treatment consultations of a second group of 20 women were digitally videotaped. Several days later, these women and their physicians (separately) viewed their own consultation to describe their DM process and identify the behaviours that facilitated or inhibited involvement in DM. All interviews were taped, transcribed verbatim and analyzed. **Results**: Part 1: Most women wanted high quality information soon after diagnosis but many felt that they were left in a void until the surgical or even the medical oncology visit. Most women thought they were heavily involved in a TDM process before, during and after the consultation. The results of the Part 2 pilot testing indicated that videotaping the consultation was feasible. Women liked the opportunity to review information presented in the consultation. They identified how they were involved in the DM process and different ways that the oncologist facilitated or inhibited their involvement. Conclusions: This study has identified women's perceptions of their involvement in the TDM process, how treatment decisions were made and physicians' behaviours that enhanced or impeded their involvement in TDM. This information will be useful to patients and physicians for promoting patient involvement in TDM.